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PC-FACS (Fast Article Critical Summaries for Clinicians in Palliative Care) provides hospice and palliative care clinicians with concise summaries of the most important findings from more than 100 medical and scientific journals. If you have colleagues who would benefit from receiving PCFACS, please encourage them to join the AAHPM at aahpm.org. Comments from readers are welcomed at pcfacs@aahpm.org.

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Summaries With Commentaries

Brain Moderators Supporting the Relationship Between Depressive Mood and Pain

Background. Pain and depressive mood commonly exhibit a comorbid relationship.¹⁻³ What brain mechanisms moderate the dysphoria-pain relationship?

Design and Participants. This exploratory analysis of data from a previous study in healthy, non-depressed, and pain-free individuals determined whether higher levels of depressive mood are associated with increased behavioral pain

responses and the neural moderators supporting this postulated relationship. Participants completed the Beck Depression Inventory-II (BDI-II), a measure of negative mood/depressive symptomology, and provided pain intensity (PI) and pain unpleasantness ratings in response to noxious heat (49°C) during perfusion-based, arterial spin-labeled fMRI. Moderation analyses were conducted to determine neural mechanisms involved in the hypothesized relationship. Bivariate correlational analyses, multiple regression analysis, linear mixed models, and ANOVA were used.

Results. Participants (n=76) were 53% female and mean (SEM) age 27 (.58) years. Higher BDI-II scores were associated with greater PI ($P=.01$, $r=.3$) and unpleasantness ($P=.006$, $r=.31$), and PI-unpleasantness correlation was high ($P<.001$; $r=.94$). A temperature of 49°C (vs. 35°C) produced activation in the primary somatosensory cortex corresponding to the stimulation site, bilateral thalamus, cerebellum, secondary somatosensory cortex (SII), inferior frontal gyrus, anterior/posterior insula, and supplementary motor area ($P<.001$) as well as deactivation in the bilateral prefrontal cortex and posterior cingulate cortex/precuneus ($P<.001$). Between-subject differences in PI were negatively associated with supramarginal gyrus and angular gyrus activation ($P<.001$, $r=-.42$). There were no positive correlations between neural activation and PI. One SD above mean neural activation ($t_{(72)}=3.64$) in regions supporting the evaluation of pain (ventrolateral prefrontal cortex and anterior insula) and sensory discrimination (SII and posterior insula) moderated the relationship between BDI-II and PI ($P<.001$).

Commentary. The feeling of pain is a subjective experience. Negative effect in individuals goes hand in hand with higher pain sensitivity,⁴ lower pain tolerance,⁵ greater activation in the primary somatosensory cortex, and deactivation in the bilateral prefrontal and posterior cingulate cortex as noted in this study. In addition to depressed mood, indicators of maladaptive coping behavior, such as a history of alcoholism or tobacco use, have been associated with higher pain expression in chronically ill patients.⁶ For optimal pain management, targeting the ascending nociceptive tracts with opioids such as morphine may be inadequate without addressing distressed effect and maladaptive coping behavior. Medications such as duloxetine, an antidepressant, and tramadol, which binds to the μ -opioid receptor and inhibits reuptake

of norepinephrine and serotonin in the CNS, can be useful for pain management.

Bottom Line. Depressed mood attenuates pain expression and moderates areas in the brain that modulate sensory-discriminative and executive function.

Reviewer. Rony Dev, DO, University of Texas, MD Anderson Cancer Center, Symptom Control & Palliative Medicine, Houston, TX

Source. Adler-Neal AL, Emerson NM, Farris SR, Jung Y, Coghill RC, Zeidan F. Brain moderators supporting the relationship between depressive mood and pain. *Pain.* 2019;160(9):2028-2035.

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Caring for Unrepresented Adults Patients at the End of Life

Background. Unrepresented adults lack medical decision-making capacity and have no identifiable surrogate.¹ What are the end-of-life decision-making processes and treatment outcomes for patients with legally appointed professional guardians?

Decision Making by Professional Guardians

Design and Participants. This retrospective cohort study characterized end-of-life decision-making processes and treatment outcomes for professional

guardian—represented decedent patients who received care at inpatient and outpatient Connecticut Veterans Affairs (VA) facilities (2003-2013) and whose last month-of-life care was documented in the VA record.

Results. Patients (n=33) were median age 71 years (IQR=60-81) and 100% male, and 60% of them were nursing home residents. Thirty-seven percent had dementia and 31% had psychotic disorders. The guardian sought judicial review for 33%, and there were delays in decision making for 42%. In the last month of life, 29% of patients were admitted to the intensive care unit, intubated, or underwent cardiopulmonary resuscitation; 45% received hospice care. Judicial review (22% vs. 60%; $P=.049$) and high-intensity treatment (26% vs. 70%; $P=.026$) were less common when patients' preferences information was available.

Ethical Challenges in Care

Design and Participants. This study performed semi-structured interviews with key stakeholders (across multiple sectors in an urban county) who participate in the care of or decision-making process for unrepresented adults. Interview questions explored the current process for proxy decision making and potential alternatives.

Results. Participants (n=25) were healthcare, social service, and legal professionals. All stakeholders identified ethical challenges, and major themes were: prioritizing autonomy (expressed by 10 interviewees; patient autonomy is prioritized above other considerations, particularly by the courts), varying safety thresholds (how to decide whether autonomy infringement is warranted), distributing resources fairly (expressed by eight interviewees; comments included balancing societal expenses and "people with more money have a lot more choice"), and taking a moral toll on stakeholders (expressed by eight interviewees; we must "also think of the impact that making these sorts of decisions has on the individuals that have to make the decisions and how we as a system can have a more trauma-informed approach around that").

Commentary. Guardianship, or conservatorship, is put in place by the courts when patients are permanently unable to make medical or financial decisions. They are either court-appointed professional guardians or relatives/acquaintances of the patient. These two studies investigated the decision-making processes of guardians in end-of-life situations. In Cohen et al., 89% of the patient cohort were represented by professional guardians who were attorneys. Almost half (42%) of the patients had delays in decision making, generally because of the guardians requesting judicial reviews, and 29% ended up

receiving high-intensity hospital care at the end of life. Both of these situations were less common when the patient's preferences were known and suggest that earlier advance care planning efforts can improve guardians' decision-making abilities. More complicated situations occur when patients never have the capacity to voice their preferences.

To improve care in unrepresented patients, it is important to be able to delineate the ethical challenges. Verma et al. used semistructured interviews with professionals from the fields of health care, social services, and law who were involved in caring for patients without available decision makers. Familiar themes were identified. The values inherent in decisions made by guardians on behalf of incapacitated patients are not dramatically different, but how the familiar ethical norms are balanced may differ slightly.

Bottom Line. There is little research on the methodology of end-of-life decision making by professional guardians for unrepresented adult patients. Earlier advance care planning may help simplify this process for guardians and healthcare teams while at the same time better ensuring decisions are made in concurrence with patients' wishes.

Reviewer. Erin Zahradnik, MD, University of Chicago, Chicago, IL

Sources. Cohen AB, Benjamin AZ, Fried TR. End-of-life decision making and treatment for patients with professional guardians [published online ahead of print July 13, 2019]. *J Am Geriatr Soc.* <https://doi.org/10.1111/jgs.16072>.

Verma A, Smith AK, Harrison KL, Chodos AH. Ethical challenges in caring for unrepresented adults: a qualitative study of key stakeholders. *J Am Geriatr Soc.* 2019;97(8):1724-1729.

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Influence of Socioeconomic Factors in the Last Year of Life

Background. Low socioeconomic position (SEP) is a risk factor for worse health outcomes.¹⁻³ How do socioeconomic factors influence end-of-life care and with what magnitude?

Design and Participants. This review identified, synthesized, and quantified existing evidence on the association between SEP and last-year-of-life healthcare use (including place of death, acute care, specialist palliative care [SPC] and nonspecialist end-of-life care, advance care planning, and quality of care) and

reported how SEP has been measured. MEDLINE, EMBASE, PsycINFO, CINAHL, and ASSIA were searched without language restrictions (inception-2019). Empirical observational studies from high-income countries were included, and the Newcastle-Ottawa Quality Assessment Scale (NOS) evaluated methodological quality. The overall strength and direction of associations was summarized, and where sufficient comparable data were available, adjusted odds ratios (ORs) were pooled and dose-response meta-regression performed.

Results. Two hundred and nine studies were included (mean NOS score=4.8); 112 high- to medium-quality observational studies were used (54% North America, 31% Europe, 8.5% Australia, and 7% Asia). Versus people living in the least deprived neighborhoods, people living in the most deprived neighborhoods were more likely to die in a hospital vs. at home (OR=1.3, 95% CI=1.23-1.38, $P<.001$), to receive acute hospital-based care in the last 3 months of life (1.16, 1.08-1.25, $P<.001$), and to not receive SPC (1.13, 1.07-1.19, $P<.001$). For every quintile increase in area deprivation, hospital than home death (1.07, 1.05-1.08, $P<.001$) and not receiving SPC was more likely (1.03, 1.02-1.05, $P<.001$). Versus the most educated (qualifications or years of education completed), the least educated people were more likely to not receive SPC (1.26, 1.07-1.49, $P=.005$).

Commentary. The US government attempts to curb costs, yet a large percentage of healthcare budgets continue to be spent on a small percentage of beneficiaries with serious illnesses. States are building capacity for and initiatives are being funded to advance palliative care in specific populations; however, this study demonstrates an imbalance in access to SPC for the poor. Socioeconomic inequality is an umbrella for the many subsets of this disparate group. Prior studies have examined distrust, education, referral patterns, funding, or other cultural reasons as potential etiologies for the imbalance in available SPC in this sector. Future studies should include socioeconomic factors along with how to access these populations and best provide care in these settings. Programs should reach out to low socioeconomic communities to improve their access to SPC and hospice care.

Bottom Line. Lower socioeconomic status negatively impacts many aspects of care, in particular access to SPC and death in the hospital.

Reviewer. Jane E. Loitman, MD MBA FAAHPM, Washington University School of Medicine, St. Louis, MO

Source. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last

year of life: a systematic review and meta-analysis. *PLoS Med.* 2019;16(4):e1002782. <https://doi.org/10.1371/journal.pmed.1002782>.

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Comparing End-of-Life Treatments for Nurses Versus the General Population

Background. Physicians often recommend/provide end-of-life care for patients that differs from what they prefer to receive themselves at the end of life.¹⁻³ Do nurses experience better quality care and less intensive end-of-life services than the general population?

Design and Participants. This observational study determined if nurses' personal healthcare experience with serious illness and end-of-life care differs from the general population. Women participating in the Nurses' Health Study (NHS) cohort aged ≥ 66 years were linked to their Medicare fee-for-service claims data. The care of women with Alzheimer's disease and related dementias (ADRD) or congestive heart failure (CHF) was compared with propensity-matched cohorts drawn from a random 20% national sample of Medicare beneficiaries. Care characteristics during the first year postdiagnosis and the last 6 months of life were measured. Two-sided t-tests, χ^2 , and logistic regression were used.

Results. Among 57,660 NHS participants, 7,380 had ADRD and 5,375 had CHF; 3,227 ADRD patients and 2,899 CHF patients died. First-year care was similar for NHS and the national sample: hospitalization rates, emergency visits, and preventable hospitalizations. Ambulatory visits were higher for NHS participants with ADRD (13.1 vs. 12.5 visits; $P<.01$) and CHF (14 vs. 13; $P<.001$). In patients with ADRD, nurses were less likely than the national sample to use life-prolonging treatments like mechanical ventilation

during the last 6 months of life (11% vs. 14%; $P=.001$) and to die in a hospital with an intensive care unit stay (10% vs. 12%; $P=.03$; 50% vs. 48% died in the community; $P=.05$); nurses were more likely to use hospice (59% vs. 55%; $P<.001$). CHF end-of-life results were similar.

Commentary. This study focuses on nurses' use of health care when managing ADRD and CHF compared to the general population. Results show nurses received similar quality of care within the first year of diagnosis but slightly increased rate of hospice enrollment the final 30 days of life. This demonstrates that experience managing serious illness and high health literacy only marginally affects the care nurses receive at the end of life. When compared to studies focused on physicians in the end of life, results were similar. This presents the question, what influences treatment? A potential explanation is that the structure and processes of healthcare systems that favor more invasive interventions drives end-of-life care independent of patient preferences.⁴

Bottom Line. Nurses' education and experience only lead to small differences in end-of-life outcomes but no difference in quality of care received 1 year after diagnosis of serious illness.

Reviewer. Dashima Carthen, MD FACP, Visiting Nurse Services of New York, New York, NY

Source. Bynum J, Passow H, Austin A, Carmichael D, Grodstein F. Serious illness and end-of-life treatments for nurses compared with the general population. *J Am Geriatr Soc.* 2019;67(8):1582-1589.

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The Growth and Demand of the Specialty Palliative Care Workforce

Background. Specialized palliative care (PC) teams improve outcomes for the steadily growing population of people living with serious illness.¹ Can the specialty PC workforce meet the growing demand for its services?

Design and Participants. This study used 2018 clinician survey data to model risk factors associated with PC clinicians leaving the field early and modeled the PC workforce population using simulations of policy changes. PC specialty society members were electronically surveyed regarding work characteristics and burnout. Multivariable logistic regression, chi-square, and Markov modeling were used.

Results. Physicians (n=551) were 50% aged 36-55, 55% female, 86% white, and working median 50 hours/week; nurses (n=1,035) were 43% aged 36-55, 95% female, 94% white, and working 40 hours/week; and social workers (n=397) were 51% aged 36-55, 95% female, 92% white, and working 40 hours/week. Overall, 50%-62% reported high professional fulfillment. Burnout was reported by one-third of respondents (no difference by clinical role). Respondents reporting burnout had 1.4 (95% CI=1.09-1.80; $P=.0075$) times the odds of intending to leave early (versus physicians; nurses [1.61; 1.26-2.05] and social workers [1.92; 1.41-2.61] had higher odds). Respondents with poor (vs. good) work-life balance had 1.36 (1.09-1.69) higher odds of intending to leave early. Modeling projected that physician numbers will decline to 6,660 in 2033 and not return to their 2019 level (7,618) until 2045. However, with policy changes to dramatically increase the number of fellowship positions and reduce burnout, only a slight decrease to 7,413 physicians in 2024 would occur, with a peak of 16,145 in 2059. In that scenario, physician numbers reach a level in 2036 that is not achieved in the base case until 2059.

Commentary. It comes as no surprise there are not enough specialty palliative clinicians.²⁻³ Burnout may exacerbate this crisis by causing clinicians to leave the field early. This is problematic given the demographics of the palliative physician as noted in this survey: more than 40% are over the age of 55 and approximately one-third work part time. At present we cannot easily absorb the loss of any providers, particularly as our services expand to care for an aging population. The authors' findings of the forthcoming "workforce valley" are alarming and may even underestimate the depth of the impending nadir as higher workloads lead to worsening burnout and potentially lower retention. Preventative efforts aimed at improving emotional exhaustion may

curtail burnout and increasing fellowship slots may replenish the coffers, but it will not be sufficient. Policies aimed at improving primary palliative care capacity are needed.^{4,6}

Bottom Line. Significant policy changes are urgently needed to address a forecasted generational PC clinician shortage.

Reviewer. Kyle Neale, DO, Cleveland Clinic, Cleveland, OH

Source. Kamal AH, Wolf SP, Troy J, et al. Policy changes key to promoting sustainability and growth of the specialty palliative care workforce. *Health Aff (Millwood)*. 2019;38(6):910-918.

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Effects of Palliative Care Consults in Pediatric Patients

Background. Pediatric palliative care (PPC) includes symptom management, advance care planning (ACP), and emotional, spiritual, and psychological support.¹⁻² What is the relationship between PPC, ACP, and circumstances of death for pediatric patients?

Design and Participants. This review (in a large, multidisciplinary tertiary care center in Iowa) identified differences in ACP preferences and outcomes at the time of death between patients who received PPC consultation and those who did not, with an interest in rural disparities. Data abstracted for pediatric patients, who died between 2012 and 2016, included demographics, diagnosis, location of primary unit, hospice involvement, goals of care (GOC), code status,

physician orders for life-sustaining treatment (POLST) completion, and location of death. Descriptive statistics were used to characterize the sample. A multivariable logistic regression was used to obtain associations between PPC involvement and ACP.

Results. Two hundred and fifty-six of the 558 deaths received PPC (commonly respiratory disease and malignancy), and the remaining 306 did not (commonly trauma). Sixty-two percent were from urban areas, 13% large rural areas, 13% small rural areas, and 11% isolated areas. The largest number of deaths occurred among those 0-30 days old (24%), and PPC was highest among this age (n=78). PPC involvement increased 37%-57% (2012-2016). Patients receiving PPC were more likely to have had ACP addressed ($P<.001$). After adjusting for covariates in the model, PPC patients were more likely to have their GOC documented (odds ratio [OR]=97; $P<.001$), have completed a POLST (OR=24; $P<.001$), have do-not-resuscitate code status (OR=7.7; $P<.001$), have hospice involvement at the time of death (OR=12; $P<.001$), and die at home (OR=2.2; $P<.05$).

Commentary. Our specialty focuses on a supportive presence, relationship development, and difficult conversations, and this paper demonstrates how that work results in measurable outcomes for patients. Although the study shows the expected benefit of palliative care consultation around the time of death, it does not describe the impact of palliative care on quality-of-life metrics. Moreover, it also reveals that there still are many families of children who die who could have benefited from palliative care services and did not receive them. The uncertain prognosis and fluctuating clinical trajectories of children with complex chronic conditions often makes timing of palliative care consults challenging, but the benefit of early consultation would enable more families to have deeper engagement around GOCs, space for ACP, discussions around preferences for location of death, and the support of hospice involvement.

Bottom Line. PPC significantly increases the likelihood that a patient/family's goals are identified, documented, and respected.

Reviewer. Megan J. Thorvilson, MD MDiv, Mayo Clinic Children's Center, Rochester, MN

Source. Harmoney K, Mobley EM, Gilbertson-White S, Brogden NK, Benson RJ. Differences in advance care planning and circumstances of death for pediatric patients who do and do not receive palliative care consults: a single-center retrospective review of all pediatric deaths from 2012 to 2016 [published online ahead of print June 21, 2019]. *J Palliat Med*. <https://doi.org/10.1089/jpm.2019.0111>.

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Analyzing Decisions Making by People in Pain

Background. Chronic pain affects 1 in 5 people and has been shown to disrupt attention.¹⁻² What is the effect of pain on everyday decision making?

Design and Participants. This 2-part study investigated whether pain disrupts everyday decision making. In study 1, an online-recruited general population sample reported whether they currently were in pain and whether they had any recurrent pain conditions. They completed 2 tasks: the shopping-decision task used by the Money Advice Service and the decision outcomes inventory (DOI), which measures real world outcomes of everyday decisions made over the previous 10 years. In study 2, healthy participants completed an extended shopping-decision task with their hand in warm or painfully cold water. Analyses included t-tests, ANCOVA, and mixed ANOVA.

Results. In study 1 ($n=1,322$) there was a main effect of current (but not recurrent) pain ($F_{(1,1309)}=5.36$, $P=0.021$, $\eta^2=.004$), where those with pain during the study made more errors on the shopping task ($M=2.86$, $SD=1.69$, 95% $CI=2.68-3.04$) than those who were pain free ($M=3.11$, $SD=1.85$, 95% $CI=3-.3.23$). There was a main effect of recurrent pain on DOI scores ($F_{(1,778)}=4.73$, $P=.030$, $\eta^2=.006$), where those with recurrent pain reported more negative outcomes from their past decisions ($M=13.8$, $SD=7.6$, 95% $CI=12.78-14.81$) than those without ($M=15.18$, $SD=8.95$, 95% $CI=14.45-15.91$). In study 2 ($n=44$), there was no effect of pain condition on number of correct answers ($t_{(43)}=0.74$, $P=.464$, Hedges' $g_{av}=.095$; Pain $M=18.89$, $SD=9.23$, 95% $CI=16.08-21.69$; Control $M=18.14$, $SD=6$, 95% $CI=16.31-19.96$). However, there were more incorrect answers in the pain condition ($M=7.43$, $SD=5.83$, 95% $CI=5.66-9.21$) than control ($M=4.66$, $SD=2.47$, 95% $CI=3.91-5.41$; $t_{(43)}=3.94$, $P<.001$, Hedges' $g_{av}=.608$).

Commentary. Patients with chronic pain often report difficulty with concentration. This is a well-

designed study that demonstrates an association between current or recurrent pain and disruption of high-level mental functions. Recurrent pain had a negative effect specifically on outcomes related to practical decisions. Study 1 was conducted with online tools only, and both studies' populations were highly educated: Study 1 had 54% of participants reporting a university degree, study 2 was conducted on university students. These characteristics limit the applicability of the outcomes to the general population and specifically to lower socioeconomic strata.

Bottom Line. Pain is associated with negative effect on cognition that may worsen over time in patients with chronic pain.

Reviewer. Giovanni Elia, MD FAAPM, University of California San Francisco, San Francisco, CA

Source. Attridge N, Pickering J, Inglis M, Keogh E, Eccleston C. People in pain make poorer decisions. *Pain*. 2019;160(7):1662-1669.

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Rave Reviews

Warth M, Kessler J, Koehler F, Aguilar-Reaab C, Bardenheuer HJ, Ditzen B. Brief psychosocial interventions improve quality of life of patients receiving palliative care: a systematic review and meta-analysis. *Palliat Med*. 2019;33(3):332-345.

The wide variability in format, setting, and duration of psychosocial interventions makes it hard to evaluate their potential impact. This review focused specifically on "brief" psychosocial interventions (at most 4 sessions delivered in fewer than 3 weeks) because these may be the most feasible for patients nearing the end of their lives. Taken together, the 17 reviewed interventions were associated with improved patient quality of life and reduced emotional and existential suffering when compared to control groups. Because these brief psychosocial interventions are relatively easy to deliver and relate to these important patient-centered outcomes, we should endeavor to integrate them into standard palliative care.

Treanor CJ, Santin O, Prue G, et al. Psychosocial interventions for informal caregivers of people living with cancer. *Cochrane Database Syst Rev.* 2019;6: CD009912. <https://doi.org/10.1002/14651858.CD009912.pub2>

Informal caregivers of patients with serious illness like cancer may experience negative physical and psychosocial health as a consequence of their caregiving demands. This review synthesized data from studies testing interventions designed to improve caregiver well-being. Wide variability in content and format made it difficult to draw conclusions. Taken together, caregiver interventions tended to improve caregiver quality of life immediately after they were delivered but without durable impact. They did not seem to impact caregiver or patient anxiety, depression, or physical health outcomes. Because it remains unclear how to consistently support caregivers, more rigorous and transparent research is needed.

Gonella S, Basso I, De Marinis MG, Campagna S, Di Giulio P. Good end-of-life care in nursing home according to family carers' perspective: a systematic review of qualitative findings. *Palliat Med.* 2019;33(6):589-606.

End-of-life care is becoming more common in nursing homes. What family caregivers need in this setting is relatively unknown. This review of 18 qualitative research studies found that caregivers endorse core tenets of palliative care: expert symptom-management, spiritual support, time to explore and honor end-of-life wishes, communication regarding what to expect, and shared decision making. Primary palliative care, if not subspecialty palliative care, should be standard in all nursing home settings.

Park CL, Pustejovsky JE, Trevino K, et al. Effects of psychosocial interventions on meaning and purpose in adults with cancer: a systematic review and meta-analysis. *Cancer.* 2019;125(14):2383-2393.

Meaning and purpose in life are associated with emotional, spiritual, and physical well-being and are commonly threatened in the context of serious illnesses like cancer. This review evaluated the effects of psychosocial interventions on the specific outcome of meaning and purpose. In sum, psychosocial interventions improved patient-reported meaning and purpose, especially when the intervention was designed to target this outcome. Because meaning and purpose are key to existential well-being, palliative care clinicians and researchers should consider targeting this outcome in their work.

PC-FACS Feedback

We appreciate your feedback. Help us help you—send your comments to pc-facs@aaahpm.org.

PC-FACS was created in 2005 by Founding Editor-in-Chief *Amy P. Abernethy, MD, PhD, FACP, FAAHPM*. The Academy is deeply grateful to Dr. Abernethy for creating this important publication and for her many contributions to the field of hospice and palliative medicine.

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